

## ESSAYS AND CREATIVE WORKS

### What the Medical Model Can Learn From the Case of the Colorblind Painter: A Disability Perspective

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**Abstract:** The author of this reflection is someone who has lived with hemiparesis throughout her entire life, yet has chosen to work as a physical therapist and professor of neurological impairment within the rehabilitation field. She brings her perspectives to the evaluation of the color-blind painter, whose story was shared in the classic book of Oliver Sachs' *Anthropologist from Mars*. Using the Brandt-Pope Model of enabling-disabling continuum, the reflection begs the questions so often avoided by the medical model, what if fixing the problem is not the sought answer? What if the normal curve has lost appeal?

**Key Words:** Mr. I, cerebral achromatopsia, artist

The case I will present in this paper is that of the color blind painter, *Mr. I*. Based solely on the case description of Oliver Sachs in his classic book, *Anthropologist from Mars* (Sachs & Wasserman, 1996), *Mr. I* was a career fine arts painter who developed a rare condition called cerebral achromatopsia. In this condition, disruption of eye to brain pathways prevents cognitive interpretation of color from otherwise normal, healthy neural signals from the eyes. Even though a person may have perfectly understood concepts of color prior to the onset of the condition, the neurological means to further process visual cues in color are now absent (Heilman, 2003). In cerebral achromatopsia, the person's eyes may still distinguish color contrasts and intensities, but the re-ordered mind can only discriminate and interpret the visual world in shades of gray.

My reflections on Mr. I's story will examine common assumptions of the medical model, assumptions that living with a disability challenges on a regular basis. It will also pose questions that challenge the presumptions of the normal curve, a curve which sees disability only in its fringes, a curve whose presumptions appear indifferent, often ambivalent, about non-normative features of life, including occupation, vision, and ability.

#### Meeting Mr. I at the Juxtaposition of Then and Now

In the following paragraphs, I will first introduce *Mr. I*, and then reframe his case using the disabling-enabling model (*Figure 1*) presented by Brandt and Pope (Brandt & Pope, 1997). Within that particular discussion, I will analyze some of the paradoxical elements of the case, especially in light of traditional rehabilitation notions. Finally, I will conclude the paper with my own reactions to the case study.

Who was *Mr. I* when the story began? He was a successful artist whose world seemed enlarged by the phenomenology of experiential color. He was described as a tall, gaunt man with a sharp intelligent face, characteristics that were seemingly continuous

pre- and post-morbid. His fingers were stained with nicotine, suggesting a nervous energy besides. In his adult life, he pursued relationships with the likes of Georgia O'Keefe, an artist who has been described as one of the great artists of the 20th-century, for her intimately compelling, yet starkly detailed representations of the beauty of the American landscape (PBS, 2006). Like O'Keefe, he too painted in detail, but his dimensions varied from large backdrops for Hollywood sets to small and typical canvases, working the paint with a more expressionistic bent. During his art career, he also worked both as an art director and as a commercial artist. His exposure to and critical appreciation of art was clearly expansive, very physical, intellectual, energetic, diverse, and emotional.

The shift in his story began with a fender bender, and a subsequent headache, which because it represented an impending cerebral vascular accident, a stroke, would turn the tide. From that late 'one afternoon' in time, he emerged as a person with stroke generated acquired color-blindness, a very rare cerebral phenomenon, as most colorblindness is congenital. As introduced above, his cerebral achromatopsia correlates to a deficit in the way the brain translates its visual stimuli into the experience of color (Damasio, Tranel, & Rizzo, 2001). It has no direct connection with the understanding or memory of colors. These attributes *Mr. I* maintained in a strong categorical way. It is also different from a more common clinical problem- color agnosia, in which one's objective perception of color lacks the associative cognition to recognize or name the color.

After the eventful afternoon of his accident and his antecedent or subsequent stroke (this was not entirely clear), he no longer saw the world in its dynamic of living color, but rather in mixes of black, white, and grey, colors associated with anything but vibrancy. He could look at familiar items, especially his paintings, and describe the colors he remembered them to be. The memory files from his countless days of working color into his artwork, his peculiar artist- eye admiration of the world, his appreciation of other works of art, remained. But, suddenly one of the greatest loves of his life- color- was gone-replaced by impressions he found distasteful and repugnant, dirty off-whites and grey black rat colors. The colorful aesthetics he had found endearing in food, faces, clothes, pets, art, and environmental contexts were so severely altered that he, at first, retreated from them.

His life was changed not only in his visual sets, his lost experiences of color, but also in his social life, his expressions of sexuality, and his ability to continue his occupation. He found that this foreign residual gray tone world was neither desirable nor predictable. Black and white films, which would have seemed to offer some familiar solace, lent instead images he could not interpret easily. Some aspects of them were harsh and unwatchable. Additionally, depending on the lighting, he could not find needed objects he sought, including his dog.

### Meeting Mr. I at the Emergence from Then to Now

As an artist, he was familiar enough with the entire spectrum of colors to commit to memory their detailed reference numbers. Using this numeric knowledge, he began to map his acute experience of the lack of color by descriptively re-inventing his color

wheel with his remaining colors as they fit into his known perceptual matters and their phenomenon, the sky and its sunsets, the ocean and its surf. The color wheel that resulted was a working grid of numerically logged and matched shades of greys. This effort connected him to his old world, his remembrance of its living colors, but positioned him in greys, number by number, color by color. Using his subjective sense of color, he simply re-calculated what he saw of the world. Via this exercise, the blacks, whites, grays, and the tones in-between were no longer simply a lack of color- they were technically identifiable hues. This was important to him, even though he could not see the colors himself. It gave his shaken world stability.

Following his stroke, Mr. I was followed closely by a team of neurologists and specialists who were trying to understand what had happened from a medical standpoint. Because of the rarity of achromatopsia, they felt obligated to test him for hysteria. During that neuro-psychological testing procedure, he could consistently and correctly identify colors by his own exacted schemes, furthering their suspicions that the symptoms were psycho-somatic. At that same time, however, he consistently failed the tests that certain garden variety color blind patients fail. Thus, they were able to rule out hysteria. Even still, their answers about his condition were elusive.

As is common in the medical profession, when in doubt, deference was made to technology. Commonly, the computed tomography (CT scan) or magnetic resonance imaging (MRI) is chosen for diagnostic radiologic study of the brain. In his case, although both means were employed, neither his CT scan nor his MRI were able to provide medically based explanations for why he was experiencing an absence of color in his perceptions of the world, his mental images, and his dreams: why color remained only in his intellectual memory. Sachs describes it “as if his chromatic past had been taken away...totally excised...leaving no trace” (Sachs & Wasserman, 1997).

His early moods, as one could imagine, fluctuated between depression and agitation. His identity, well-being, and competence had been dealt a severe blow. Acute responses to new bodily impairments are real, proving to be disorientating, reactive, and depleting (Williams, 1999). Slowly though, over the course of a year, *Mr. I* moved toward acceptance- acceptance that his condition might not change. With the transitions incumbent upon acceptance, he became very curious and interested in the workings of his own brain. While medical experimentation had offered little to organically change the course of what had happened to him, it did afford a finding or two that lent to small but very significant changes. One finding was that he had his best visual acuity within a green spectrum. With the provided green tinted lenses, *Mr. I*’s contrast vision was enhanced remarkably and immediately. A sudden acute delight ensued as he discovered a means by which he could enhance his recognition of forms and boundaries. He regained some control over his vision losses.

In addition to this outcome, acceptance also fostered his choice to return to painting again. While the process was explorative and therapeutic as well as artistic, it afforded a familiar environment and context for his rehabilitation process. His early artworks were prolific and extremely intense in their grey tones. His later works waxed

more sophisticated and complex. Though his eyes would not be benefactors of any color palette, he eventually even approached the matter of how to insert color into his pictures, experimentally adding various hues to his otherwise grey tone painting. This required a certain passage of time.

While nothing could take away the magnitude and gravity of his loss, not even that passage of time, still, it seemed that as he painted through his loss, the process itself became pivotal. It seemed to progress him from acute raw desperation to astounding epiphany. He moved from surviving the loss to eventually thriving beyond its void. One of the things that strongly influenced his *clinical* course was the experience of what Sachs described as an *apocalyptic sunrise*. This infused meaning into his visual realities and awakened something in him - a simple sunrise seen differently than ever before. The combination of what he saw and how he saw it- a perspective gained with his own eyes and his own interpretations- represented another turning of a tide. As he afforded himself canvas to express this in re-created images, a whole new impulse and valuation of his way of being took wing. Somewhat deliberate, somewhat intuitive, and very much a part of preserving his art within, he began a reconstruction of his identity. He found new sensibilities and experiences that were contingent on this found world without color.

Little by little he became almost wholly redefined- both by his experience and a certain forgetting of what was lost. With less concern felt for what was behind him, he turned from former orientations, habits, and strategies to find new attributes and assets.

This transformation freed him to actualize his affinity to different characteristics of life than he had previously known. He accepted and pursued his preferences for low light, twilight, and night. He relished the night and found coherence and completeness in it. He redefined his vision not as impaired, but instead as highly refined, privileged, and uncluttered. In the end, when offered a possible cure by his medical team, he found the offer repugnant, unintelligible, and disruptive. He chose to keep his gains in the world of achromatopsia.

This transformation from a life disrupted to one discovered was not kept private or hidden as something stigmatized or unimportant, but instead shared by experts in the medical field, readers of his story, and the audiences of his art. His artwork and his story, through their representation of his different way of seeing, enable/enabled others to find a perspective they might not otherwise know. As members of the “typically seeing” population explored his perspectives, many reported his work to be incredible and inspirational. His renewal as a whole person was clearly personal, but it simultaneously re-constructed the privilege of vision for others to experience vicariously.

#### Understanding Mr. I and His Transformation: What It Offers the Waking World

From the standpoint of the enabling-disabling model, *Mr. I* is first seen as an accomplished artist who, chain smoking aside, was complete within his known world. He could stretch his limits and find no restrictions to his artistic freedom. With the advent of his impairment, the loss of color, his world shrunk for him. It was almost as if the stroke

had found his Achilles' heel. The meanings and definitions of his aptitudes and passions were so integrally related to color, that it was worse than stripping or shrinking (though that is technically the model), it was enlarging his world in all the wrong ways, not making him too big for his surroundings, but too small. Surrounded by wrong, he did not belong anymore. The once close fit he'd known through an intact sense of color changed to distaste, incoherence, aversion, and saddened emptiness. His own reactions together with the abeyance of the medical model's uncertainties moved him toward a disabling process, a distancing from his inherent strengths and assets, loves, and occupation.

As we look at his transformation from the perspective of the enabling-disabling model, there is clearly a time when he begins to move in a different direction on the continuum, toward meaningful restoration of his person, his efficacy, his competencies, his dreams. His mobilization enlarged his world through environmental modifications, renewed personal commitments, functional restoration and... time.

To begin, we can outline the causes of his limitation as atypical visual impairments with no known cure or correction. We can attest to the further impact of his co-morbid and correlated mental health matters- depression, agitation, and even suspected reactions of hysteria. We can presume that he faced prospective income problems, and with his loss of interest in intimacy with his wife, marital concerns. His initial self-perception of achromatopsia was grave, almost hopeless. His use of the medical field for directives reflected this in its intensity, desperation, and exhaustion. He was a man suspended from the self he had known with no direction back or forward.

The paradox of the story can be seen at once, just by his entrance onto the medical stage: he presents as an artist with atypical color blindness. The medical team frantically reviewed the situation, then the literature; they brought their tests, then sorted through their files of expertise and their medically minded paradigms; there were no clinical pathways for an artist who could not see colors. Without a known cure, the best contribution from all their efforts was seemingly their suggestion that *Mr. I* try green lenses, offered on the basis of sophisticated visual testing. That suggestion proved one of the only enabling contributions borne of a pure medical model's approach to his visual impairment. To their credit, they did rule out hysteria, all the while, offering him assurance that his MRI and CT scan were normal.

The medical professions were quick to assume that news of normal would be a comfort to the receiver, as if the symptoms will be less bothersome, resting on the laurels of such news. Their eventual offer to try to experimentally restore *Mr. I's* color world would seem to be their most noble effort of all to stay true to assumptions of normal as preferable, a pinnacle of modern science. Interestingly, however, by the time that next best thing to a miracle offer came, *Mr. I* had already moved on from what was then to what was now. Just where the medical field had ended its journey, at their patient's choice to turn from a fix, *Mr. I* had begun his own.

For those most comfortable with precepts of the medical model, it may seem strange that *Mr. I* chose not to pursue their heroic endeavors to try to rectify his

impairment. They may find it paradoxical that someone would forever give up a world that they had so loved, of light and color. They may question whether such a person could or should really ever forget or move away from the curve called *normal*. They may find that Mr. I's validation of his own experience is not real, instead a cop out, a way of hiding his true distresses and regrets. They may question whether anyone besides the impaired *Mr. I* will truly gain from the sharing of his unhealed epiphanies, rather suspecting that any apparent outside interest may be borne of sympathy, not intrigue. They may find it incompatible to consider a loss as window to an enlarged perspective.

But what seems clear from what we read about *Mr. I* is that he did move beyond his impairments, using means that can be elucidated well via identified vectors on the enabling-disabling continuum, (Brandt & Pope, 1997), and by trusting that normal is normal for whoever defines it. Environmental modification is as important as modifications in a person with impairments. What most enabled *Mr. I* was night time. By accommodating his own visual needs and becoming a night person, he began to feel at home. Another environmental modification was the addition of green lenses. Both of these environmental changes enabled him to make the most of his residual visual function.

The other vector that accompanies rehabilitation is functional restoration. This was accomplished by his eventual return to painting. The agency of his limited vision was incorporated both into his identity as an artist and in his artistic perspectives. It was re-framed as an asset rather than a deficit, described not in terms of loss, but as something found, new, unique, uncluttered, highly refined, and privileged. He emerged as a painter with a new medium, color refined by and defined in its absence. Interestingly, his greatest restorative processes involved no direct modification of his impairment, rather that its features were embraced, managed, used, and studied.

One other enabling-disabling concept is the "symbolic mat", an undergirding safety net that serves to support a person via social and physical environments (Brandt & Pope, 1997). Pictorially, the more this mat is displaced by the person's impairments and needs, the less effective it is in lending support. For the mat to support *Mr. I* best, this suggests that he (at least in part) abandon his norms of old. The physical and social environments that best can support him now would necessarily include respect for his new-found works of art, his night time preference, and his own visual perspective. Short of such an environment, he will only experience great displacement of the symbolic mat, equating with a short fall of support. In other words, if asked to function within a world with no modifications, he will almost certainly experience a disadvantage.

The personal journey that *Mr. I* experiences over time- the gravity of loss, his painting through it, his unexpected epiphany, his use of canvas as faith in his new paintings, his forgetting of the past, and his shift to time ahead rather than always looking back were critical to his exploration of what lay beyond normal. His new sense of self-attributions and understandings of grey, his completeness in night-world, and his empowered semantics of refined versus impaired vision were all signs that he felt increasingly at home in his new life. His choice of saying no to a fix of his color

blindness ascertained that *Mr. I* did not see himself as a new member of a stigmatized group, not as one less than his former self. In fact, with *Mr. I*'s sharing of his new perspectives with the medical field and his community, one might interpret that his discoveries were highly valued by him. Thus, in his personal journey, he walked away from many assumptions of normal.

In examining the impact of his impairment on his quality of life, it is apparent that he transitioned from a clear functional impairment to a transformed place in which he established a high quality of life within his deficiencies. By entrusting to himself and his vision new understandings and perspectives, he was able to explore and open up countless re-defined possibilities. The trade-off was giving up of the old, then the inevitable and certain neurological forgetting of the past.

His wife and her transformations were not addressed by Sachs, though that relationship likely represents part of the cost of disability. We don't know what it felt like to her to lose what might have been or whether she was even able to grasp his new world, much less with enthusiasm. We aren't told if *Mr. and Mrs. I* stayed happily married or what a staying in the marriage may have meant in terms of her own compromises. We know neither the weight of those things nor whether her relationship with her colorblind mate grew comfortable and familiar, inspiring, or acceptable.

Likewise, even with his successful environmental transformations, won't there still be environmental challenges that *Mr. I* will face each day? Will the environment of the night prove satisfying long-term, non-discriminating, offering the cultural support he needs for his art and his creative well-being? Will his art, more unusual and less commercially desirable, stay satisfying and financially solvent? Will his intelligence and strength transform into eccentricity as his world views perpetuate in a color seeing world? Will his newly created and constructed self-efficacy continue to develop from its infancy forward? Will he cope with his nervous artistic personality in ways that are healthful or will his old habits (smoking in particular) continue a little worse for the added wear? Will *Mr. I* be more naturally inclined to spirituality and life-long learning with his grey scale bias? Will that inclination make up for the likely short fall in other areas? Will he sense the tether of enabling and disabling contexts more as he ages? Will nostalgia for old fits sneak up on him, will he regret saying no to medical interventions toward a cure?

All these represent psychological and social environments that will interact with his person as he ages with achromatopsia. This seems bound to create rocky places and times of self-doubt. His course seems prone to isolation at times, misunderstanding, frustrations, and identity crisis. That there will be on-going dynamics in this case is a given. These dynamics will continue to reverberate within and around *Mr. I*. The course they will take is not fixed. While his story has clearly turned in an optimistic direction from its rough and tumultuous beginning, the metamorphosis described in this paper seems an ironic blend of tenuous and tenacious. Unlike the somewhat wrapped up package of a story of *Mr. I*, the real *Mr. I* may eventually find the world a bit wearisome and it, in turn, may grow less delighted in all that makes him so different from them. His

world views may become less palatable to people up close than they are in the comfortable distance of a great story.

### Parting Commentary from the Peanut Gallery

My reaction to his story comes from at least two and half perspectives. I am an artist. I am also someone who grew up with right hemiparesis, the identical twin to someone without hemiparesis.

As an artist, it is almost impossible to imagine the world without color. I envelop myself in the world's hues. When I recall a hike or a storm, I see it vividly in color. I study faces and the color of eyes. I use colors to describe my moods, even changes I feel in my world view. Color immerses me with larger concepts, coolness, subtlety, fierceness, peace. When I was learning to speak Japanese, I recall discovering that Japanese had but one word to describe both blue and green: Aoi. When I realized this, I could not imagine how blue and green could ever be captured in the same word. I felt protest. But as I lived there, that protest was overtaken by a warm and wonderful charm. Blue could be bigger and mean more than I had ever considered. That understanding absorbed my preconceived notion of a smaller blue peacefully. It emerged my favorite color in the end and remains so today. It is a consecrated member of a palette I adore. If it were my only color, would I let go of the rest willingly?

When someone asks me what impairment I fear the most, I have often said, being blind. The thought of such a loss can trigger a visceral horror. That is what I felt at the thought of Mr. I's loss, too. Though it was not the complete blindness that I most fear, it was a tortuous blindness. It acted as a thief that stole only the very belongings that *Mr. I* most valued, leaving the rest behind. Left-overs littering the voids left behind by loss of what a person most treasures/cherishes may prove an echoing torment. I related to his struggle to accept what was left of his vision. I truly admire the faith he put in his transformation.

While I cannot imagine how *Mr. I* actually transformed his visual realities, I *can* imagine the transformation that comes to a person as it relates to a physical impairment. Certainly, I have wished that my slow and clumsy right side could feel the dance that sways right and left and twirls without falling, or the rush of skiing down a hill with perfect sense of coordination and control, or the ability to play a guitar with proficient dexterity and skill. I have looked at my twin and wished I had her body for a day. I have begrudged my scrapes and trips and dropped wine glasses. I sometimes have felt that my strong left side was not enough for the dances I would have danced. But because it was enough for the dances I did dance, I am who I am.

As I have matured into who I am today, I can relate to Mr. I and his reconstructionist ways. The attributes I treasure most in myself are intertwined with this profound little impairment of mine. My choice of occupation is an outgrowth of it. I even feel privileged for the perspective having right hemiparesis has lent me including the kindred connection I feel with many of my patients, with left handers, with artists. If



given the chance to experience some of the things I always wondered about, I find myself saying, “That might be nice for a day, but why?” Perhaps, had that chance been afforded me when I was young, and I didn’t yet know my world through what are now my own experiences, I’d say, “Sure.” But part of the world I have known is more whole because of a weak right side. I have grown into it like a vine that is guided by an arbor. I have come to believe that cerebral palsy has gifted me with more wholeness than fragmentation, more meaning than bedlam. I am satisfied that the opportunities and doors it has opened are just alright with me. I like the world where my gained perspectives thrive.

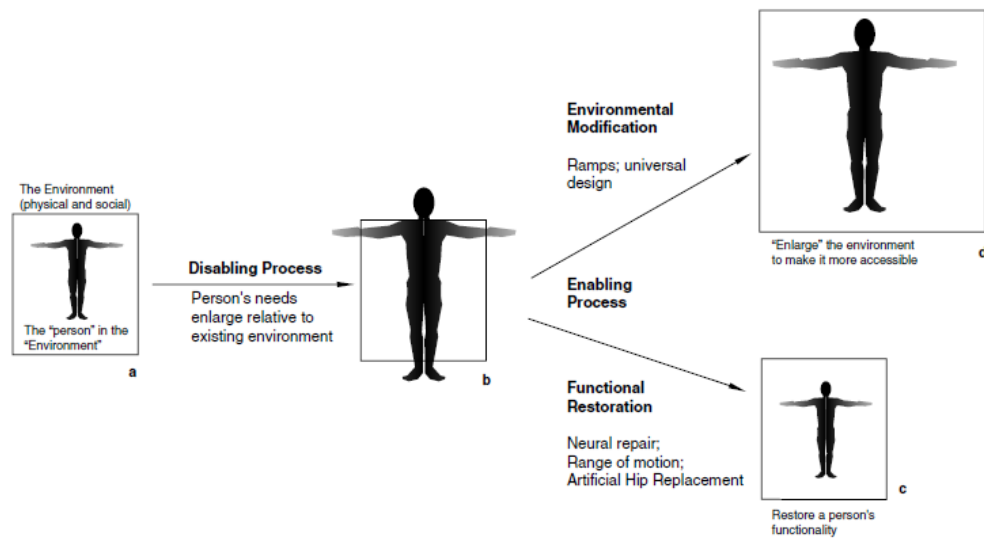
All this said, I both related to Mr. I’s story and believed it to be true. It wasn’t fabricated as a cheap explanation. The paradox is real, but it is no more real than its counter-part- the very real tragedy of growing up too normal to break free.

**Sheryl Holt** is a career physical therapist who is currently completing her PhD in rehabilitation science while working as an assistant professor in the doctor of physical therapy program at Wheeling Jesuit University. She has lived successfully with hemiplegic cerebral palsy while serving children with disability for over 30 years.

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#### Appendix



**FIGURE 1** Conceptual overview of the enabling-disabling process. The environment, depicted as a square, represents both physical space and social structures (family, community, society). A person who does not manifest a disability (a) is fully integrated into society and “fits within the square.” A person with potentially disabling conditions has increased needs (expressed by the size of the individual) and is dislocated from his or her prior integration into the environment (b) that is, “doesn’t fit in the square.” The enabling (or rehabilitative) process attempts to rectify this displacement, either by restoring function in the individual (c) or by expanding access to the environment (d) (e.g., building ramps).